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ABSTRACT

The study investigated the effects of P.L. 94-142 (the Education for All Handicapped Children Act) on parents with disabled children through case study procedures with six families and a series of structured interviews with 26 additional families. Children ranged in age from 6 to 18 years and in degree of developmental disability from moderate to mild. Four factors most commonly articulated about parents' experiences with the individualized education program were the first IEP meeting, information gathering, subsequent IEP meetings, and monitoring. Among findings were that most parents had very little idea of what to expect at the meeting or of what was to be expected of them; that parents sought IEP related information from administrators, teachers, and other parents; and that the most prevalent source of IEP conflict related to the inclusion of specialist services in the child's education plan. The least restrictive environment (LRE) was considered in terms of risks, benefits, and academics and ideology. Conclusions regarding the LRE included that almost all parents ultimately supported decisions to integrate their children with nondisabled peers; that the fundamental risk perceived by parents was that of their child being tolerated rather than taught; and that what mattered most about their child's educational placement was the quality of interpersonal life it promised. Three images of parents emerged: parents as partners, parents as advocates, and parents as pioneers. (SB)

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The Impact of Public Law 94-142

on

Parents of Disabled Children

A REPORT OF FINDINGS

U.S. DEPARTMENT OF EDUCATION
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The authors gratefully acknowledge the contributions of Margaret Roberts, Joan Klein and Joseph Blatt to the development and conduct of this project. We are especially indebted to the parents of disabled children whose views and experiences we have tried to represent as faithfully as possible. We trust that their many hours of teaching will prove worthwhile.

This report is designed to stand alone as a final and complete description of the findings from our two-year investigation of the effects of P.L. 94-142 on families with disabled children. For purposes of focus and clarity, however, and to avoid unnecessary repetition, the preparation of this report assumed the reader's general familiarity with the course of the investigation as documented systematically throughout the project period.

Useful accompaniments to this report are the comprehensive Final Reports submitted to BEH at the conclusion of each of the two project years. There the interested reader will find detailed narrative accounts of the case study families which have not been included in this report. In addition, while the investigative procedures are summarized in the present report, full descriptions of the sample and methods can also be found in the Final Reports.

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Chapter 1

INTRODUCTION

During the Vietnam era, critical observers of the fourth estate often noted that while the public was generally informed about the big battles, it was the soldiers who remembered the little incidents. This is a report about soldiers...parents of disabled children, really. But as it turns out, the metaphor is more apt than convenient.

The organization of this Report of Findings reflects one purpose accomplished in two ways. The purpose is to illuminate and understand the effects that P.L. 94-142 has had on parents with disabled children. The ways, most simply put, are that of the parents, as reported in Chapter 3, and that of the investigators, as reported in Chapter 4. The former are expressions of collective experience and belief; they represent subjective truths as perceived and recounted by the parents in the present investigation. The latter are insights and impressions, based on the investigators' having lived with the data--and with the sources of the data--for almost two years. The former are not, in any meaningful sense, open to question or refutation. The latter invite both.

One introductory comment on the nature of this investigation needs to be offered here to provide as clear a context as possible for the understandings reported in what follows. Soon after initiating the case study activities, it became necessary for the investigators to disregard traditional objectivity in order to preserve both credibility and trust within the developing parent relationships. Thus, in addition to

assuming the roles of observer and examiner, the investigators also became confidantes, counselors and colleagues at different times throughout the project period. Even, on occasion, babysitters.

Consequently, while the information reported here as findings results primarily from a series of structured interviews, it is also, to an unverifiable extent, augmented by informal observations, unavoidable eavesdroppings and coffee cup deliberations. The examiners, in other words, found it necessary to participate in the worlds of the people being examined. The net effect of this participation (i.e. the development of open and trusting personal relationships with the sample members) was, in our estimation to enhance the quantity and to enrich the quality of the information received.

Chapter 2

PROCEDURES

A thorough description of the sample and the methods of the present investigation is provided in the Draft Final Report (submitted to BEH in August, 1980). For present purposes, each is only briefly reviewed below.

A. Overview

The information presented in this report was gathered during a 16 month period beginning in February, 1979, and ending in May, 1980. For the first 6 months, 6 families with disabled children participated in case study procedures as reviewed below. This participation continued for all but 1 of the families into the second year of the project, at which time a series of structured interviews was conducted with an additional 26 families. Because the case study data and the interview data proved substantially complementary, no attempt was made for purposes of this report to distinguish the findings according to format.

B. Case Study

1. Sample

The 6 families originally selected to participate in the case study were identified after the investigators met with more than 60 parents of disabled children in the Greater Boston area. The sample was chosen primarily on the basis of the parents' active and extensive involvement in self-described "battles" with the educational establishment over the delivery of quality education services to their children; these parents were described by their peers as well known "movers and shakers" among the parent community. The extent to which the children represented in the sample were educated in integrated settings was considered less important for present purposes than the extent to which their parents demonstrated a history of confrontations with school officials to ensure delivery of those services which the parents judged adequate and appropriate for their children.

The SES levels of the participating families ranged from Low to Upper-Middle, with 4 of the families living in densely populated urban areas. The children ranged in age from 6 to 18 and in degree of developmental disability from Moderate to Mild. Four of the 6 children remained in substantially separate special education classes throughout the course of this investigation, with 3 of the 4 non-integrated children considered by their parents to be appropriately placed for the present time.1

2. Method

Six visits to each of the families' homes were scheduled at regular intervals throughout the course of this project, during which time the investigators compiled a detailed record of each child's educational history and of the parents' (and others') roles in determining that history. Each interview lasted

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1. Because one of the children was found not to require special education services at the end of the project's first year, this family did not continue participation in the second year.

approximately 2 hours and was structured to facilitate parents' recall as well as to ensure that discussion was generally both task oriented and pleasant. Ample opportunity was also provided at each meeting for parents to digress, reflect, elaborate and editorialize on the events recounted during each visit.

In addition to this primary means of information gathering, investigators also encouraged parents to contact them at any time to report on ongoing incidents in their child's educational experience. The frequency of parent-initiated phone calls ranged from 3 times weekly to bimonthly across all families, with each call lasting, on average, 25 minutes. Also, in the 3 instances where IEP meetings were scheduled for children represented in the study, the investigators attended the sessions as observers.

The case study procedures were sustained with little change throughout the project's second year with 5 of the 6 originally participating families. The frequency and duration of structured visits were reduced, however, to roughly half of those conducted in the first year. Because information was also being gathered during this time from a new sample of parents (see below), case study interviews encouraged parent's reactions to the experiences being reported by others as well as to thematic trends in the developing data as explained by the investigators.

C. Structured Interviews

1. Sample

Twenty-six parents, representing 30 disabled children, participated in structured interviews conducted, in parallel with the case studies, during the second year of the project. Only parents of children in integrated educational placements were selected for participation.1

The children represented in the interviews ranged from 3 to 17 years of age with disabilities including: epilepsy; spina bifida; cerebral palsy; retardation; learning disabilities; and a range of reported emotional and behavior problems. Seventeen of the children were integrated with non-disabled peers in public school settings for more than 60% of each school day; thirteen were integrated for periods ranging from 25% to 60% of their daily schedule.

2. Method

The interview instrument was developed to elicit from parents a detailed accounting of their experiences, reactions and attitudes regarding their child's education in mainstreamed settings. Parents were asked about their familiarity with the specific provisions of P.L. 94-142, both as written in the legislation and as applied to their individual situations. They were also asked to dentify specific ways in which the implementation of P.L. 94-142 affected them and their children both positively and negatively.2

Each interview lasted approximately 2 hours. In 7 of the 26 instances, a follow-up meeting was required to complete or elaborate upon aspects of the interview.

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1. For reasons of scheduling and of parent preference, the interviews were conducted with mothers only in 19 of the 26 families.

2. A copy of the interview instrument is included in the Year II Mid-Term Report submitted to BEH on March 31, 1980.

Chapter 3

FINDINGS

This chapter organizes the results of parental experience, as determined by the case studies and structured interviews, according to the IEP (Individualized Education Program) and LRE (Least Restrictive Environment) provisions of P.L. 94-142. Because parents in the present investigation consistently reported minimal, if any, direct experience with the legislative provisions relating to Due Process or to Protection in Evaluation Procedures, neither is explicitly addressed in what follows. When sufficient information warrants, however, appropriate reference to these latter provisions is included.

A. The Individualized Education Program (IEP)

> The school system is educating the teachers. They have the courses they're taking, learning about P.L. 94-142. They can get a lot of information out of a book, but they don't know David, they don't know Spencer... Each child is an individual. I think it's the responsibility of a parent to say, 'Look, you know about retardation, or you may know about CP or whatever, but for my particular child, this is what I think you should know.'
>
> Mrs. L.

As a topic of concern, the IEP meeting, with its associated opportunities and responsibilities for parent/ professional collaboration, generated more discussion and substantially more emotion in the present investigation than did any other single issue related to parents' experience of P.L. 94-142. In what follows, the effects of this provision are summarized according to four factors most commonly articulated by parents: 1) The First IEP Meeting; 2) Information Gathering. 3) Subsequent IEP Meetings; and 4) Monitoring.

1. The First IEP Meeting

> At my son's first IEP meeting I got this impression that I'm sure a lot of other parents got, too: 'You're dumb. You don't know anything. We're the school department. We know it all.'
>
> Mrs. F.

There are distinct phases, parents report, in their children's educational history which can only be recalled with difficulty; the facts, for whatever reason, have become fuzzy, the picture irretrievably incomplete. The first IEP meeting will never be counted among those phases. This experience, they claim, will remain indeliby etched, in graphic and generally painful detail.

With only slight exception, the parents' first collaborative encounter with professionals proved at best unfulfilling. For the most part, it proved distressing, depressing and, oddly enough, useful in ways none would have anticipated; it was to provide a standard of performance and satisfaction, the repitition of which most parents became compelled to avoid.

Two aspects of the first IEP meeting are most frequently recounted by parents to characterize their experience:

a. Poor Preparation: Most parents had very little idea of what to expect at the meeting or of what was to be expected of them. They lacked basic descriptive and procedural information that, they say, might have readied them more adequately for their collaborative responsibility. Acknowledging an incomplete understanding of their new rights, many parents were also uncertain of what they were supposed to contribute in the way of evaluative information concerning their child.

In general, parents report, they didn't know that they should have known more.

b. Professional Intimidation: Parental accounts of the professionals' behavior toward them during the first IEP meeting suggest that the parents were not the only members insufficiently prepared to fulfill the collaborative responsibility. The professionals, they claim, talked at them, talked about them, even talked down to them, but only rarely made an effort to communicate with them. Attitudes among the professionals reportedly ranged from barely tolerant to blatantly unwelcoming; in addition, the parents were overwhelmingly outnumbered.

Frustrated both by the apparent collegial pretense and an inability, often, to penetrate the professional jargon, parents found themselves forced to suppress opinions and suggestions which afterwards they believed might have contributed usefully to the development of an educational plan responsive to the needs of their child. Most distressing was the collective sense among parents that despite their lack of formal credentials, they possessed unique, valuable information about their child which was to go either unoffered or unheard.

Often these potential contributions were to compete unsuccessfully with the meetings' more primary concern over budgetary matters and limited program availabilities.

Like themselves, parents reported, even their children were at times disregarded by the professionals within the meeting.

The harshness and severity of the parental recollections in these instances are only minimally countered by the several sample members who, themselves, were special education professionals. The fact that these fortunate few received such distinctly different (e.g., respectful) treatment within their first IEP meeting suggests that, as a group, the non-professional parents may not have been too extreme in their reports. For them, the initial IEP experience was disappointing, demeaning and, as reported below, ironically instructive.

It must be stressed here that despite the parents' negative reactions to the initial IEP experience, almost all, in fact, were generally satisfied with the outcome of the meeting. That is, parental complaints related only minimally to the educational plan formulated for each child. It remains therefore a curious but consistent finding throughout this investigation that parents generally attended to and, by their own report, were more affected by process variables associated with P.L. 94-142 than with actual outcomes.

2. Information Gathering

> The way we find out what we need to know is the same nitty-gritty way that parents of handicapped kids have always found out--through word of mouth, through other parents. The big flaw is that the system does not tell you anything.
>
> Mrs. O.

Of the two aspects which parents describe as contributing most to their negative initial IEP experiences (e.g., poor preparation and professional intimidation), there was only one on which they could act directly. By improving upon their own readiness to participate in subsequent IEP sessions, not only would they ensure less personal frustration, but, some believed, they might also influence professional receptivity toward them; they would become more respectable colleagues.

As a result, most parents recognized the need to be better informed, practically and politically, about the IEP process and about the full complement of their rights under P.L. 94-142. Too, many discovered they needed to be better prepared to deliver the information about their children that each knew only they, as parents possessed. This latter, they report, was less a case of gathering additional information than of organizing and learning how to present their wealth of information more effectively.

Parents sought IEP-related information from three categorical sources: a) Administrators; b) Teachers; and c) Other Parents. Their assessments of the usefulness of each source is summarized below.

a. Administrators are described as juggling too many diverse concerns to be particularly responsive to the needs of individual parents. As a group, therefore, these representatives of the educational establishment are reportedly approached least of all by parents seeking information; in cases where they have been approached, the resulting parent satisfaction has been minimal.

b. Teachers are generally reported to be reliable allies in the parent search for information specific to the programming needs of their children. They are perceived as more invested than the administrators in the children's future and have, on occasion, offered parents advice on how to perform at the IEP meeting to help ensure that future.

c. Other Parents of disabled children, particularly those who have "been through it all before," are consistently reported to be parents' most valued, trusted and useful sources of information. They comprise an informal technical assistance network, always accessible, from which parents report learning about IEP strategy as well as IEP substance.

With little exception, parents reported that their motivation to avoid a repetition of the first IEP experience caused them to pursue informational paths which, in turn, led to their increased competence and confidence in the face of subsequent IEP sessions. In addition, many note that they came to view their constructive participation in the next IEP meeting as a critical necessity. For regardless of the changes in meeting membership that could be expected to occur from year to year, they alone would be the spokespersons, indeed the source for continuity.

It is important to emphasize that the preparation itinerary on which most of the parents in the present investigation chose to embark required considerable commitments of time, energy and individual resources. Whether or not the appropriate or, in some sense, ideal itinerary would, in fact, require as many stops as the parents judged necessary is indeterminable from the present investigation. However, it is unreasonable to assume that all parents of disabled children could or would be able to make the kind of commitment to information gathering that was demonstrated by the present sample. This then raises a most important question to which the present investigation is not in a position to respond: What are the consequences that await parents less able or less willing to initiate efforts to improve upon their initial IEP performance? Are these parents destined to keep repeating what appears to be the universally negative personal experiences associated with the initial IEP meeting? Or might the apparent benefits of parental information

gathering be otherwise brought to bear by the presence of a parent/child advocate? These questions, and the issues of prediction and practicability which they raise, ought to receive prompt careful attention in subsequent investigations.

3. Subsequent IEP Meetings

> When you put it all together--all the information that you're hearing from different people, and all the things that you're beginning to see for yourself--you realize that if anything's going to happen, you're going to have to really fight for it and make it happen.
>
> Mrs. C.

As parents became more knowledgeable about the needs of their children and more sophisticated in the ways of the IEP procedures, they came to expect that differences of opinion would arise between themselves and the professionals on matters pertaining to the adequacy and appropriateness of their children's educational plan. What was to distinguish these conflicts from previous similar clashes was the parents' perceived ability to influence their outcome. This time, they claimed, they were sufficiently confident and much more adequately prepared to argue their convictions.

By a wide margin, the most prevalent source of IEP conflict related to the inclusion of specialist services in the child's educational plan. In the typical instance, parents wanted more of one or another such service than the school system was willing to provide. Most often, conflicts of this nature were resolved without resort to formal appeals proceedings; they were resolved, parents report, by their working in concert with the professionals toward effective compromise. However, while only a few parents in the present investigation did find it necessary to enter into appeals proceedings, all acknowledged that the legal opportunity for them to do so contributed reliable, if hidden, leverage to their negotiating position. By the time of the second IEP meeting, in stark contrast to the first, there were no parents unaware of their right to due process. It was considered to be their silent negotiating partner.

It is important to note that parents' assessments of subsequent IEP meetings as more satisfactory were based exclusively on criteria related to interpersonal process. In effect, one could fairly paraphrase their logic as: "We performed better. We made ourselves heard. The meeting was more satisfactory."

Understandably less prominent among the parents' assessment criteria were variables relating to the outcome of the meeting which may have affected their children's educational plan. As mentioned above, parent dissatisfaction with the first IEP meeting had little to do with outcome variables; these had already been judged as more or less suitable. In the present instance, therefore, parents' increased satisfaction with subsequent IEP meetings was based on subjective perceptions that their own efforts had paid off. The IEP meetings were better, they reported, because they themselves were better. Of the two negative aspects associated with the initial IEP meeting, they had acted significantly and with success upon the only one within their capacity to affect.

4. Monitoring

> The only way I can get them to deliver what they promised is to fight. And the fight isn't over once the IEP is developed. Sometimes getting them to implement it is twice the battle.
>
> Mrs. J.

Increased involvement in the development of educational plans for their children did not, for most parents, end with their performance at IEP meetings. Instead, wary of the school system's intent and/or ability to deliver on the "paper promises" developed and consented to at the meeting, most parents reported having no alternative but to monitor programmatic activities vigilantly. Not unlike the impetus that propelled them to become better informed in the first place, they describe their "watchdogging" responsibility as a necessary reaction to the incompetence, deceit and lack of caring they have come to expect from the school system.

As they have become more actively involved, so it appears have parents become less trusting of the educational establishment.

Many parents are quick to differentiate the character of their monitoring from that which might be expected of parents of non-disabled children (and indeed from that which they, themselves, perform with regard to their own non-disabled children). Theirs, they report, is rooted more in suspicion than in general interest. Unlike the parent who may be curious to know what the school is currently doing with their non-disabled child, the parents in the present investigation see themselves looking out for what the school isn't--but in accordance with the IEP, ought to be--doing.

Parents of non-disabled children keep in touch. Parents of disabled children keep on top. They send notes to teachers asking specific questions about daily schedules, activities and the possibility of problems. They request meetings rather than wait to be invited. And, on occasion, they "pop into the classroom" or they "wander on over around recess time" to observe the proceedings.

The parents in the present investigation point to two kinds of school system behavior which they believe justify their skeptical reactions: a.) Chance Discoveries; and b.) Lack of Responsible Communication.

a. Chance Discoveries: Parents report instance upon instance in which they "just happened to find out" that elements of their child's IEP were being systematically ignored. From discussions with teachers, with other parents, and often from a casual remark made by their child, parents learn that what they had assumed to be programmatic assurances described in the IEP were, in fact, never acted upon. Specialist services, for example, the frequency of which may have been agreed upon through skillful compromise during the IEP meeting, are discovered not to exist at all. Or the extent of integration which parents expected their child to be experiencing in any given school day has, for the past two months, been reduced to half of what was mandated in the IEP...and again the parents were never directly informed.

b. Lack of Responsible Communication: Explanations offered by school system officials for lapses in IEP implementation may or may not prove acceptable to parents (e.g., staff attrition, overcrowding, temporary equipment shortages). What is consistently unacceptable, however, is the condition in which such explanations are offered only after discovery of the problem by parents. Only rarely were parents notified in advance that unexpected modifications in an IEP plan may be required. The impression, therefore, with which parents are left is twofold: Either the school is unaware of discrepancies between the printed and practiced versions of a child's IEP or, more galling, it doesn't really care that such discrepancies exist. Otherwise, parents argue, why wouldn't the school make it easier on everyone involved by being "up front" about implementation problems?

Apart from the obvious distress and mistrust that such school behavior causes among parents of disabled children, it also requires that they act in ways which then lead the school to regard them as "troublemakers," as "selfish," even as "spies." Aware that none of these is a stereotype which, if sustained, bodes well for the enhanced parent-professional relations necessary for responsible fulfillment of the legislative mandate,

still, in the view of the parents, their options to act otherwise are non-existent. The vicious cycle, they report, seems inescapable; they are being indicted by irresponsible others for acting responsibly.

B. The Least Restrictive Environment (LRE)

> I can't tell you for sure what I want, but I know I don't want her sorting popsicle sticks the rest of her life.
>
> Mrs. R.

Just as parents perceived participation as the issue most in need of address and resolution in their IEP experience, so was it reported to be their fundamental concern with the LRE provision. There was, however, one obvious and critical difference: "Participation" in the IEP referred to the parents; in deliberations over the LRE, the referent was their child. This difference was to significantly affect the manner in which parents assumed and fulfilled their LRE-related responsibility.

Almost all of the parents in the present investigation ultimately supported decisions to integrate their children with non-disabled peers in public school settings.1 They arrived at their decisions, however, only after considerable equivocation. Reporting less than complete confidence in their ability to evaluate the interpersonal and programmatic trade-off's such a decision implied, they nonetheless undertook careful examination of what they perceived to be the primary risks and the primary benefits associated with the child's participation in an integrated educational setting. These are each reviewed below to illustrate the complexity of the LRE decision-making challenge as experienced by parents.

1. Although the terms "LRE" and "integrated placement" are not synonymous, we have used them interchangeably in this section to represent the parents' understandings as accurately as possible.

1. Risks

> If only the teacher would just level with me and say 'I don't know anything about Down Syndrome.' I would understand that. Maybe I could even do something about it.
>
> Mrs. J.

a. Personnel Preparation: Parents feared that as a consequence of limited familiarity and the likelihood of inadequate training, regular education staff would be ill prepared or inclined to accept their disabled children into the mainstream. Just as their child's physical appearance and behavior may have frequently elicited awkward reactions from neighborhood passers-by, parents worried that teachers, too, would respond anxiously, unnaturally, defensively in the classroom. How, they wondered, could teaching happen under these conditions?

In addition, assuming familiarity over time, parents questioned whether teachers would be sufficiently understanding of their child's disability--and capability--and of the implications these may have for his or her learning styles.

The fundamental risk, parents reported, was that of their child being tolerated rather than taught, of their child being allowed to take up space, but not necessarily subject matter, in the classroom. Almost every parent in the present investigation pointed to the stagnating effects upon their children of this potentially very real eventuality.

b. Interpersonal Adjustment: As unfamiliar as teachers may be with children like theirs, parents worried that the non-disabled classmates would be even more so. And, because the peers would be less likely than the professionals to make an effort to mask their individual awkwardness around the disabled newcomer, parents foresaw dangerous risks to their children's self-esteem and interpersonal growth. He or she would be teased, taunted and rejected. He or she would make no new friends. He or she would be chronically miserable. Not learning, in this case, would be the milder of the effects he or she would suffer under such classroom conditions.

The segregated classroom, even when it offered little else, at least offered acceptance. Young egos weren't bruised there. Interpersonal security was assured. In the view of many parents, therefore, the segregation classroom was, at its worst, a comfortable if not necessarily constructive alternative to the mainstream. For them as well as for their children.

2. Benefits

> One day, I went up to get him after school, and I couldn't find him. He was actually lost in the crowd, looking just like the other kids. His posture, the way he walked, everything.
>
> Mrs. O.

a. Interpersonal Relationships: Balancing the parents' concern with the risk of peer relations is the potential value that these same relations could have upon their child's social and emotional development. That is, they reasoned, if the expected teasing or rejection were either minimal in degree or limited only to a few particular individuals, then the opportunity to engage regularly in mainstream activities with non-disabled peers would offer their children significant role-modeling and skill-building advantages. And too, the possibilities for enhancing self-esteem through successful peer interactions would be greater and more diverse for their children than was the case in previous segregated experiences.

Parents reported looking forward to the prospect of their disabled children building friendships in the mainstream. They wanted their children to want to be with others, a variety of others, rather than having them always in situations surrounded only by others like themselves. They wanted their children to be motivated to choose and to exercise judgment in their interpersonal relationships, as well as to experience conditions where choice and judgment are possible. They wanted their children to be valued appropriately by their non-disabled peers, to be understood, and, eventually, accepted.

None of their vision, they understood, would be realized apart from the mainstream.

Finally in this regard, there is what parents describe as the seldomly acknowledged benefit of the integrated placement: the advantages derived by the

non-disabled classmates from coming to know children like their own. Mainstreaming, they report, is almost always misperceived by educators, as well as by parents of non-disabled children, as a state of affairs arranged on behalf of disabled children alone. By ignoring the mutuality of the mainstreaming experience, parents explained, this one-dimensional representation fails to appreciate the social competencies that will be engendered among all children as a consequence of the integrated educational experience.

Parents in the present investigation offered more personal conviction than specific examples to underscore the significance of this reported benefit. They left no doubt, however, that in their opinion there were great social and emotional rewards to be gained by non-disabled classmates--as well as by teachers--from being with, learning about and befriending their disabled children.

b. Preparing (for) the Future: As reported by parents in the present investigation, the future is a time gauged in days and weeks, and occasionally in terms of upcoming school vacations. Rarely do they project ten and twenty years ahead to consider such things as college, marriage and/or careers in which their children might be involved. Rarely do they entertain visions of the future for their children in the anticipatory manner of parents of non-disabled children. In fact, parents in the present investigation entertained the future much less than they worried about their children's ability to cope within it.

It is in this context that parents identified another potential benefit of the integrated educational placement: its impact on their children's readiness to fit into, even to influence, the mainstream future. Three elements of this reported benefit are summarized below:

1. Exposure to change and to changing

Their children, parents reported, would become more familiar with a variety of contemporary lifestyles and behaviors and increasingly exposed to the rapid changes each undergoes. In contrast to the relatively invariate quality of the segregated placement, the LRE would provide a place where trends and transformations happen.

2. Schooling in hard knocks

While, as noted above, the potential of the LRE to become a social and emotional battleground for their children was considered very real by most parents, many of them also saw that battleground as the only appropriate testing ground their children could experience. That is, if the risks of interpersonal adjustment could, in time, be overcome, then the benefits of having endured non-acceptance or rejection by others might well prove strengthening. If their children realized they could take it, explained parents in reference to the school's interpersonal climate, then they would be better prepared to make it in the future.

3. Demystification

Finally, parents consistently referred to their children's having to be a visible part of the present if there were to be any changes in the attitudes and behaviors of others toward disabled children in the future. From this perspective, parents viewed the LRE as an opportunity in which their children could serve a positive catalytic purpose by being there and becoming known.

3. Academics and Ideology

> I've known all along that kids like Joey deserve better. I'm just glad that the law of the land has finally caught up with me.
>
> Mrs. B.

Notably lacking among the parents' concerns with the social and emotional consequences of the LRE decision was an expressed concern about academics. Only in rare instances did parents in the present investigation raise or respond to the salience of curricular issues in their consideration of the LRE. To them what clearly mattered most about their child's educational placement was the quality of interpersonal life it promised. That their child was well treated, well thought of and well accepted by both peers and professionals was the paramount, if not singular, objective of most parents.

Nor were parents unaware of their having slighted such things as workbooks, test scores and homework assignments in their LRE deliberations. Indeed, most fully acknowledged the importance of curriculum quality in assessing the adequacy and appropriateness of any educational setting. There were, however, two problems they, themselves, faced with such an assessment:

- In the first place, parents in the present investigation were not considering just <u>any</u> educational setting; they were trying to determine one in which <u>their child</u> would be able to participate. Fitting in, they reported, was not something for which their children were traditionally well known.

- In the second place, who are parents, they asked, to judge the rightness of an academic curriculum? Particularly in advance. What experience, what training do parents have with that? After several months, of course, they could see whether their child is learning in certain areas; but, by then, they asked so what? Way before that time they will have known whether or not their child is happy.

> That, parents report, is what parents know about. That's where they're pro's. And that's where they're concerned.

Personal considerations, then, clearly took precedence over programmatic aspects in parents' decisions regarding the LRE. There was, however, one additional element that pervaded and to a great extent made more vexing their decision-making responsibility.

From the time of their first encounter with P.L. 94-142, even those parents who did not completely understand the legislative substance applauded the legislative spirit. Each, in his or her own way, mounted the ideological soapbox frequently throughout this investigation to proclaim the virtue of the law's regard for disabled children. As a consequence, many considered their efforts to justify continued non-integrated placements for their children as reactionary, not in the spirit of things, even as musguided.

The principle of the LRE, which all parents understood to mean a maximizing of integration, proved in the final analysis to be an important factor in parental decision-making. When the risks and the benefits of integrated placement were distressingly in balance, the weight of the ideology underlying P.L. 94-142 ultimately tipped the scales.

Chapter 4

IMAGES OF IMPACT

The pathways to participation charted by P.L. 94-142 have been well travelled by the parents in the present investigation. By their own report, these parents have acted more, and have believed themselves to have accomplished more on behalf of their disabled children, than was ever the case for most prior to the legislation. In addition, as a result of the legislative responsibilities newly assumed, parents report having begun to think more optimistically about their children, about their children's potential in the larger society, and more broadly about their own possibilities as parents to help realize that potential.

Without question, P.L. 94-142 has involved and affected the parents in the present investigation to a great degree. It has also, however, required considerable commitments of their time, renewals of their confrontations with the educational establishment, and occasional swallowings of pride. Increased parental involvement--the clearest impact of P.L. 94-142--cannot, on the basis of this report, be considered unquestioningly positive.

In the following pages, we present three images of parents fashioned after the findings of the past two years: 1) Parents As Partners; 2) Parents As Advocates; and 3) Parents As Pioneers. These characterizations are offered less as conclusions than as reflections of how we have come to view the impact upon parents of P.L. 94-142. They are suggestions, provocations, speculations. They are, ultimately, assumptions at work in a very early period of the history of the new law.

A. Parents As Partners

It is impossible to point to the one particular pamphlet, magazine article, television spot, community meeting or other information outlet responsible for buoying parent expectations with regard to P.L. 94-142. To begin with, virtually all the media designed to communicate the import of the legislation to parents presented P.L. 94-142 in terms of "historic reform" or "sweeping changes." Specifics notwithstanding, there was little question about the law's unprecedented magnitude, the fact that it represented a "new era in educational services" for disabled children. In addition, as in most instances of parental information sharing, much of the drama attending the advent of P.L. 94-142 was conveyed not through formal channels but rather over backyard fences and cups of coffee. Parent to parent. Optimist to optimist. The news was bound to be good.

As indeed it ought to have been. For as parents of disabled children initially came to understand it, P.L. 94-142 would be responsible for making the people in charge of public education finally take charge of their kids as well. The incompleteness of this understanding was to become evident to parents only after they became more experienced in the pragmatics of implementation. However, because the understanding proved so central to their early problems and dissatisfactions, it is useful to examine its foundation more closely.

To the parents with whom we met, P.L. 94-142 was first and foremost a statement about participation by their disabled children in programs that, to now, had not included them. It was not as immediately clear to these same parents, however, that the legislation directed their own participation as well, in a process from which they, too, had been traditionally excluded. What was perceived and understood by parents almost immediately was the intended outcome of the legislation. The process, however, by which the educational goal of P.L. 94-142 would be achieved was, at the outset, less clearly grasped...and by some parents, not grasped at all. Consequently the parents' initial posture was that of the beneficiary, the one to whom a certain overdue promise had finally been made.

As we noted in the Introduction to the Final Report, the history of parent-professional relationships in affairs affecting disabled children has been one of scant harmony and infrequent personal satisfaction. These relationships have been widely reported by parents in terms of confrontation rather than collaboration; the professional is described more often as an adversary than an ally. We need not review here the reasons put forward by parents to support this view, nor is it necessary for our purposes to balance that view with the professionals' claims. For, irrespective of who may be at fault for this state of interpersonal affairs, the outcome, itself, is generally perceived in similar ways by both parties: e.g., neither the parents of disabled children nor the professionals from whom they've sought help, guidance and support have enjoyed a history of productive or mutually gratifying interactions one with the other.

Consistent with the spirit of progressive reform embodied in P.L. 94-142, this traditional way of relating was legislatively considered to be neither advisable nor immutable. Rather, by conferring upon parents a legitimate responsibility to participate as decision-makers in the educational planning for their disabled children, the legislation advanced a parent-as-colleague model that envisioned a substantially different procedural status quo.

In effect, the legislation formalized little more than common sense by recognizing the parental potential to contribute a quality of information and reaction that is uniquely their own, accumulated over years of varied day-to-day involvements with their disabled children. Such contributions, while they were to be no more or less influential than those of the professionals, were to be given due consideration in the development of each child's educational plan.

In retrospect, therefore, some awkwardness, perhaps even dissatisfaction, ought to have been anticipated as both the parents and the professionals sought to adjust to their new roles respectively. In our view, the experiences described by parents during the past two years are most reasonably and most usefully understood as reflecting just such an adjustment in process.

While one could interpret much of the parental reports as indicting the intended decision-making reforms of P.L. 94-142, in fact no such indictment is, in our view, warranted. For while parents have expressed much more consternation than satisfaction with their efforts to assume partnership status among professionals, it has become abundantly clear that neither they nor the professionals were sufficiently prepared to take on the mutual role obligations called for by the legislation. Some, on either side, never really saw the obligations coming; others had no idea what to do with it when it arrived.

However, after each side experienced both the process and each other in generally unprepared fashion, subsequent IEP meetings showed far greater potential for a reasonable partnership to develop. Certainly these latter experiences were reported by parents to be more satisfactory. Ironically, for the parents in the present investigation, it was the sour experiences of their first IEP involvement that prepared and conditioned them best for their subsequent professional meetings.

What is significant here, and what must be kept in proper perspective, is not that a first IEP confrontation led to a subsequent IEP collaboration, but more importantly that in the subsequent meeting parents clearly demonstrated their willingness and ability to sit among a group of professionals and deliberate with insight, skill and steadfastness about the education of their disabled children. Clearly, the unique decision-making forum intended by P.L. 94-142 is both workable and, as far as the present investigation was able to determine, in the best interests of the disabled children involved. That this outcome has not been smoothly or comfortably achieved thus far is, as we have explained, an unfortunate consequence largely of incomplete expectations and historically awkward posturing between parents and professionals. As the investigation indicates, however, neither of these factors is insuperable. As each side gains more direct positive experience with both their new responsibilities under the law and with one another, we would expect that the kinds of negative experiences reported here will be greatly reduced.

B. Parents As Advocates

There is no clearer or more consistent finding from this investigation than that parents, with the advent of P.L. 94-142, have become more substantially involved than ever before in decisions and actions affecting their disabled children's education. Indeed, over a relatively short period of time, most parents have extended the scope of their initial involvement beyond the degree of participation formally mandated by the legislation. What, for many, began as tentative, frequently awkward attempts to exploit the opportunities for involvement offered by P.L. 94-142 has, for most parents in the present investigation, developed into sophisticated, time-consuming efforts to ensure that the benefits of the legislation are made fully available both to them and to their children.

With this increased involvement has come a growing belief among parents that they, more than any of the educational establishment, are responsible for the success of their children's education. Largely as a consequence of mistrust, disrespect, and lack of confidence (in professionals, generally, and in school officials, in particular), parents have come to view the invitation to involvement extended to them by P.L. 94-142 as an unavoidable obligation. What for all was initially an opportunity has, for most, become a necessity.

The concerns which reportedly motivated the parents' involvement to degrees over and above that required by law have been, as we noted, largely negative; in this respect, parents seem to be acting more out of desperation than inspiration. They have been put on guard, they report, by school system practices which they regard as either deceptive, inadequate or ineffective. Most would prefer that both these causes and their effects were otherwise. Most would prefer to act simply in accordance with the mandate of P.L. 94-142 rather than to have to react to the individual officials responsible for its implementation. Many report they are "just plain tired." But, they add, they've learned there's a job to be done.

Despite the considerable costs--emotional, physical and temporal--presently associated with increased parental involvement, there is evidence to suggest that the situation need not--and likely will not--be enduring. As what are now the relatively novel effects of P.L. 94-142 are experienced by more and more individuals, at all levels, there is reason to believe that a more functional and mutually satisfying state of affairs will be achieved.

A primary reason for this optimistic forecast is the parents, themselves, and the kind of development they have demonstrated in a relatively brief span. By their own assessment, as well as by their actions, it is clear that parents of disabled children have learned--and are continuing to discover and to communicate to other parents--effective advocacy strategies. They are knowingly and confidently becoming a reasonable force with which the objects of their dissatisfaction will have to reckon.

Increasing numbers of parents, after having initially vague conceptions of the law, have now become almost scholarly in their knowledge of it. They know its provisions and, through practice, have come to discover where its strongest leverage lies; it is as if they've studied their cards carefully and, with experience, have learned how most strategically to play their hand. In addition, parents have also learned to become less intimidated by professionals. They've come to respect the potential value of their own contributions to the IEP process and refuse to be ignored, put down or devalued any longer. In this sense, the progression of IEP meetings described above appears to have provided an effective desensitization model; it has helped parents learn how to overcome their performance fears.

Finally, as a result of their participation parents have confirmed without doubt that they--and only they--are the ones in a position to care about and to work for the exclusive interests of their individual children. System representatives, they've discovered, look after the system above all. Parents look after their children.

None of this is to suggest that the machinery of P.L. 94-142 will, from the parents perspective, be running smoothly just ahead; any number of wheels will continue to squeak, and parents will represent the loudest among them. The point is, rather, that with each new experience the parent parts of the machinery will be running more efficiently than during the experience before. And in the closed system of the schools, this more effective functioning will likely affect all the operating components in time.

The parent responsibilities--both those required by law and those which have been self-imposed--are central but difficult to assume. And they will doubtless remain so in the years immediately ahead. Throughout the accounts of the past two years, however, we have detected not only more conviction among parents but also less wasted motion; not only renewed confidence but also developing skills. It has taken time, and it has cost more than was originally anticipated, but the parents in the present investigation have lifted themselves above naivete and ineffectuality. They've become savvy, sophisticated and strategic. They have demonstrated that parents can indeed become key actors in the legislative scenario.

In the end, we must emphatically reject any suggestion that parents are either incapable or unwilling to contribute in meaningful ways to the professional task of designing adequate and appropriate educational programs for their disabled children. While parents have yet to fully realize their potential as IEP colleagues we find no evidence whatsoever that this failure can be attributed to ignorance, reluctance or recalcitrance on their part.

C. Parents As Pioneers

It is not because P.L. 94-142 is so relatively new that we have come, during this investigation, to regard parents of disabled children as modern pioneers. We have done so instead on the basis of the actions and attitudes which they, themselves, have consistently sustained, and which so vividly resemble the images drawn by history of early settlers. Indeed, we have come to understand the persistence and the grappling of parents of disabled children as the knowingly necessary responses of individuals who are preparing for others, like themselves, to follow. For these parents, as we've seen, the challenge of the present has been daunting, the rewards of the future uncertain. Yet, not one of the individuals in the present investigation questioned either the premise or the promise of P.L. 94-142. Nor were they unaware that their concerted participatory efforts would help to forge its permanence.

Nowhere is the parent-as-pioneer characterization more dramatically exemplified, nor its motives more clearly expressed, than in the conflicts attending LRE placement decisions. As we have described, parents generally view the integration of their disabled children in regular public school classrooms as a mixed and questionable blessing. And yet they fight zealously to ensure that their children are mainstreamed to the greatest extent possible. Thus, despite their assessment that the regular public school--its personnel, its architecture and its materials--is as yet generally unprepared to respond effectively and appropriately to the needs of their children, and despite their fears that the non-disabled children may, in subtle and not-so-subtle ways reject their children, still the parents in the present investigation viewed the integrated LRE setting as the most appropriate--and desired--placement for their child.

To a great extent, it appears that parents have established their position not simply on the basis of what is immediately best--or easiest--for their children alone. Rather, they have been significantly influenced as well by what they perceive as the longer-term opportunities within P.L. 94-142 to change society's traditional way of seeing and knowing disabled children in general. There is, in other words, an almost missionary responsibility perceived by

parents to alter the historical status of disabled children in the world, a responsibility which requires that they, as parents, accept certain risks on behalf of their children by participating in often agonizing decisions to integrate them in the public school.

This is not to say that some immediate and individual benefits of mainsteaming are unrecognized by parents, principally those advantages associated with enhanced social opportunities school-wide. Indeed, as noted above, some parents even regard possible interpersonal difficulties within the LRE environment as providing their disabled children with the best possible preparation for adult life in the larger society. And, too, they are quick to emphasize that the non-disabled classmates, together with their teachers, will, themselves, gain from coming to know disabled peers with whom they've had little, if any, direct prior experience. Nonetheless, it is questionable whether these recognitions, per se, would compel parents to engage in the kinds of arduous decision-making that many have still chosen to endure. If the benefits of mainstreaming, as perceived by parents, do not clearly outweigh the potential risks, then how does one explain the pro-integration position most parents choose to adopt? More importantly, perhaps, how do the parents, themselves, justify decisions which at best leave them emotionally unsettled, wondering whether, by their support of a mainstreamed placement, they've done right by their children?

It was clearly apparent from this investigation that at least some of these consequences, some of the questioning and self-doubt, was alleviated by the parent's perceiving themselves as standard bearers in a cause extending beyond the singular concerns of their individual children. These parents, who by circumstance alone, find themselves among the first to operationalize the legislation, are acting as they are in part to ensure that the principles embodied in P.L. 94-142 are preserved and maintained. In moments of individual distress, this conviction--whether or not it is legitimate--serves a most useful justifying purpose.

There is a danger, of course, in extending the parent-as-pioneer characterization too far, in relying on its simplicity and inherent appeal to mask the host

of complexities bound up in these early stages of the legislation's progress. Our interest, however, in putting this image forward was not only to suggest a partial explanation for certain parental actions, but also to indicate one important way that P.L. 94-142 is impacting upon parents. By the obligations it has required of them, it appears that the legislation is slowly but significantly affecting, in a positive way, the manner in which parents fundamentally view themselves and their disabled children. They have been empowered to act, to take initiative and to be directly responsible for the quality of their children's education. They need no longer consider themselves simply as isolated or unsupported seekers of service.

While every parent in the present investigation questioned, to some degree, their readiness to assume this new responsibility, not one questioned his or her willingness to take full advantage of the opportunity. Each, it seems, has been emboldened and encouraged by the legislation. Acting upon it has not yet been easy, but it has been necessary; the cause--the future for their children, for all disabled children--is too vital and worthwhile.

As one listens to parents discuss the prospects for their children made possible by P.L. 94-142--prospects which most considered unrealistic only several years earlier--one is impressed by the visions they offer of a society in which their children, regardless of current level of functioning, are included. It is a vision which the parents, themselves, admit they would not have entertained prior to the legislation, a vision in which the child's disability remains unchanged, but in which its consequences--socially, educationally and vocationally--are dramatically different. It is a hopeful vision, predicated on a view of disabled children as learners, as valued participants. It is, finally, a vision which these parents, these pioneers, are working hard to ensure.